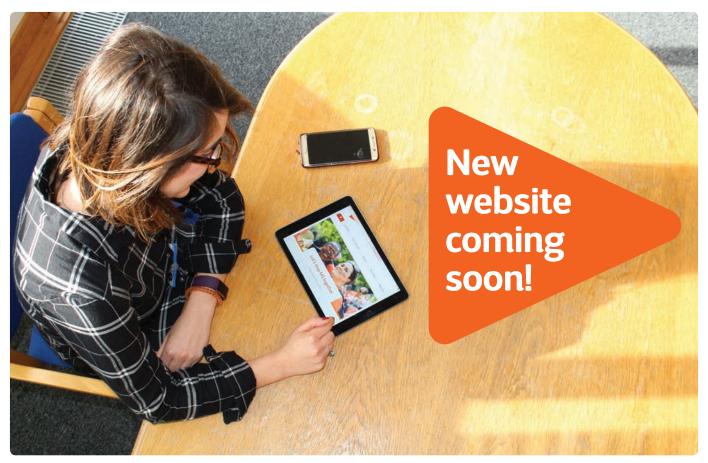


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**March 2018** 

# Teamspirit



ur new MS Society website will be launching in April. Thank you to everyone who's been involved in helping to develop the new site.

Our website is hugely important to us. It's the main way that people find us, and is a vital source of information and support for so many people living with MS. The new site will have a refreshed design, with a new look and

feel. It'll have an improved search function, making it quicker and easier to find content. It'll also have an improved 'near me' function – so visitors will be able to search for group services and activities by area. The site will be mobile and tablet friendly making it more accessible and enabling us to reach more people affected by MS.

Read more about the new website on page 2.

Team**spirit** 



### Want to share your group's good news?

Send your story ideas to us at teamspirit@mssociety.org.uk and we'll be in touch!

# New website coming soon (continued)

Before our new site launches in April we'd like to share it with you. We'll be sending you a sneak peak before launch to thank you for all your support and give you the opportunity to let us know what you think! We'll be emailing all our Group Coordinators and Group inboxes soon – so do keep an eye out.

Our website address won't be changing; you'll still be able to access it at mssociety.org.uk

Your group's MS Society email address will be displayed as part of your group's contact details. If you don't already have an MS Society email address, you can find out how to get one on our volunteer website on the 'MS Society email' page. You can also contact our Supporter Care team for further information and guidance.

We'll continue to develop the website after it launches to make sure our users' experience is the best it can be. We'll keep you updated with all developments as they happen.

Our volunteer website won't be changing for now but we'll continue to make updates to it throughout 2018.

If you have any questions about the new site, please contact our Supporter Care team.

Audience: All Action: Share

**Contact:** Supporter Care

supportercare@mssociety.org.uk

0300 500 8084

# Group and Support email upgrade

We're making lots of improvements to our IT systems over the coming months so that we can be more efficient and reach and support more people affected by MS.

As part of this, we'll be upgrading Group and Support email accounts to give you access to the latest version of Microsoft Outlook Web Access and increase the size limit of your inbox.

Your current mailbox will be unavailable for a few hours at some point between Tuesday 3 April - Friday 13 April while it's moved.

Once moved you'll need to go to <a href="https://outlook.office365.com">https://outlook.office365.com</a> to access your group's email.

Your group's username will change and become your group email address (e.g. yourgroupname@mssociety.org.uk) Your password will not change.

We'll be in touch soon via your MS Society email address to let you know when this is going to happen, along with instructions, and a guide to the main changes.

Audience: All Action: Note

Contact: John Hamblin, Head of ICT john.hamblin@mssociety.org.uk



# Do you want to recruit more volunteers?

Feedback from our Volunteers' Survey last year highlighted that volunteer recruitment is a priority for groups.

We're thrilled to announce that Online Recruitment is now live on our website at mssociety.org.uk/get-involved/volunteer/what-can-i-do under 'Volunteering opportunities'.

Through Online Recruitment you'll be able to:

- recruit volunteers online
- post volunteering opportunities automatically on sites like Do-It.org and Charity Job
- · receive and process applications

Online Recruitment will enhance current recruitment methods, rather than replace them. At the moment, there are over a hundred opportunities on Online Recruitment. In January alone, we received 36 online applications.

Full information and guidance can be found on the homepage of our volunteer website. We'll also be organising training webinars: dates and times will be available on the events pages of our volunteer website soon.

We're also refreshing our printed recruitment materials (such as posters and leaflets). Please visit our volunteer website before Friday 30 March to let us know what changes you'd like to see.

For more information and to start using Online Recruitment, contact our Volunteering team.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk

# Online training sessions coming soon!

Many of you also told us that you'd like flexible learning. We're please to let you know that from June this year, we'll be trialling online bite-size training sessions for volunteers who are part of, or thinking of joining, a Coordinating team.

These interactive online sessions will provide an opportunity to:

- learn about new and existing resources and support available to you
- meet other Coordinating team members face to face from your own home with no login needed – you can even use your smartphone
- discuss what it's like for your group and hear from others about their experiences

This is the first time we've offered online training and we want to make sure it works for you.

Please spare two minutes to fill in our online survey, which is available at www.surveygizmo.com/s3/4221375/
Online-Training to share your opinion.

We'll review your responses after Tuesday 3 April, when we'll start planning the events.

We'll let you know training dates and topics in the next edition of Teamspirit. If you've got any comments or feedback about our learning and development opportunities, we'd love to hear from you – please contact the Volunteering team.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk





# Thanking and recognising volunteers

Thank you for all your suggestions on improving the way we thank our volunteers. Based on your feedback, we've improved some of the ways we recognise our incredible volunteers.

#### **Shining Stars Awards**

Shining Stars Awards recognise the outstanding contributions made by volunteers. With your guidance, we've improved the Shining Stars process. You can nominate a volunteer at volunteers.mssociety.org.uk/volunteering-with-us/organising-volunteers

#### Thank you cards

Our newly designed thank you cards are available from our Online Shop at volunteers.mssociety.org.uk/online-shop Since the new designs were created, more than 1,700 cards have been requested!

#### Volunteers' Week

Volunteers' Week will be taking place between 1-7 June 2018. It's a fantastic opportunity to recognise and thank volunteers for their contributions. To celebrate your group's volunteers you could:

- organise an event honouring their achievements
- share stories on social media
- nominate them for a Shining Stars award
- send a thank you card

Keep an eye on NCVO's website for tips and resources to help you celebrate Volunteers' Week. And of course... a simple "thank you" goes a very long way!

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk

# Join our discussions on policy guidance

In November, we asked if you'd like to join our Volunteer Policy Guidance Panel. Five volunteers from across the UK joined us to help ensure the guidance we provide on our policies is simple, practical and easy to use.

#### Would you like to join our panel?

At panel sessions, you'll discuss what would be useful for other volunteers, and give feedback on new policy guidance. You don't need prior knowledge of our policies to get involved.

Over the next few months, we'll be reviewing the information we provide about:

- Disclosures
- Data protection
- · Social media
- Resolving volunteer issues and concerns
- Expenses

You could choose to be involved in all the panels listed above or just those that are of most interest to you. Panels take place online and we can help you use our online tools, discussion forums and videoconferencing.

For more information please contact our Volunteering team.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk



# Become a National Council member

Our Council Members are a vital link between people living with MS, our Board of Trustees and senior staff. They provide guidance on our UK-wide strategies, and ensure that the voices and opinions of people living with MS across the country are heard.

We're currently looking for volunteers to join our National Councils in England, Northern Ireland, Scotland and Wales.

As a Council Member, you'll attend four Council meetings a year, as well as other activities that connect with the MS community. Expenses are paid and we'll provide you with a full induction. Catherine Doran, Northern Ireland Council Chair says:

"Before joining our Northern Ireland Council, I was unsure of what the role involved. Now, I'm so pleased this is the route I've taken to give back.

At Council meetings, we review plans, focus on campaigning, talk about fundraising opportunities and reflect on the work we've all done to date.

Everyone on the Council has a unique perspective on MS, and every voice is heard. I have made great friends through my role and I wouldn't have it any other way."

The deadline for applications is **Thursday 3 May** (5pm), followed by interviews. Elections will take place in August and September, with results announced at our AGM on 22 September.

For more information or an application form, please contact our Governance team.

Audience: All Action: Share

Contact: Governance team governance@mssociety.org.uk 020 8827 0470

# Volunteering policy on age restrictions

From time to time people ask us about volunteering opportunities for people under the age of 18, and you may also get similar queries at a local level.

Our policy remains that we're only able to offer volunteering opportunities to people aged 18 or over.

Our Volunteer Involvement, Safeguarding and Whistleblowing policies can be found on our volunteer website at https://volunteers.mssociety.org.uk/policies-and-documents

If you have any questions, please contact our Volunteering team.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk





# New volunteer leaving process

We've recently started testing improvements to our process for volunteers when they finish their role with us. Our new process ensures that we're able to keep our records up to date and that we capture feedback from those who're leaving to make sure that we can continue to improve our volunteering experience.

If you or a volunteer in your group is planning to leave please let our Supporter Care team know. We'll update their records (ensuring we're compliant with data protection) and make sure they don't receive any further communications in relation to their volunteering role.

We'll then contact them (by email, or post if they don't have an email address) thanking them for all their incredible support, and providing a survey to gather their feedback.

Volunteers are also welcome to request a reference – we can provide information on this during the leaving process.

Audience: All Action: Share

Contact: Volunteering team volunteering@mssociety.org.uk

# General Data Protection Regulation update

As you know, the General Data Protection Regulation (GDPR) will come into effect on 25 May 2018.

We're doing lots of work to ensure that we're ready for GDPR and we want to ensure that you feel supported with these changes. We have a project dedicated to GDPR for volunteers and groups, to make sure that you're kept informed and up to date with all things GDPR. There'll be lots of support and information in the coming months, including:

- In the next couple of weeks we'll provide your group with a detailed listing of Frequently Asked Questions. Your LNO will let you know when it will be available on our volunteer website.
- We'll be providing an updated e-learning module on data protection which key volunteers and those with access to the Portal will be required to complete.
- There'll also be an update at the Spring Forums, where data breaches will be covered.
- Look out for lots of information and support on GDPR and information security in May's edition of Teamspirit.
- You can also find a list of six practical things you can do to prepare for GDPR in January's edition of Teamspirit.

If you have any questions, please contact your LNO in the first instance, or the Data Governance team for urgent queries.

Audience: All Action: Share

Contact: Data Governance team datagovernance@mssociety.org.uk





# Cannabis and MS: the law needs to change

We launched our first ever campaign action on legalising cannabis for medicinal use last month.

Evidence shows that cannabis can work for some people to relieve pain and muscle spasms in MS when other treatments haven't worked. When we asked people with MS what they thought, 72% felt that cannabis should be legalised for medicinal purposes.

Political momentum has been gathering on this issue. There's been support in the Welsh Assembly, Scottish Parliament and UK Parliament.

But to see change, we need the UK Government to take action. So in February we took the issue to MPs. Campaigners sent over 2,500 tweets and emails, reaching 616 of the UK's 650 MPs.

You can still write to your MP by visiting mssoc.uk/cannabisaction

#### Meet our Campaigns team

Our Campaigns team will be out and about meeting groups across the nations to chat about campaigning and find out what issues interest you the most. Whether your group already campaigns, or has never campaigned before, we'd love to meet you!

If you'd like to arrange a visit from us, please get in touch on the details below.

Audience: All Action: Share

Contact: Campaigns team campaigns@mssociety.org.uk

### Spring campaign

This MS Week, 23-29 April, we'll be kicking off our Spring campaign, which is all about MS research!

We'll be sharing lots of information and resources - celebrating the incredible progress that's been made so far and sharing current research developments. Later in spring, we'll be raising awareness of the difficulties people face accessing DMTs; thanks to research we now have more DMTs than ever before, we need to make sure people can access these. Keep an eye on our website and social media channels this spring for more information.

We know there's still a long way to go. And we need to continue to raise money to fund vital research. We'll be sending out a direct mail to our supporters asking them for a regular donation.

A 'template letter to editor' to send to your local newspaper will also be available. It'll include information about MS Week, research we fund and provide an opportunity for you to tell people about the services your group provides. Your LNO will be in touch with more details soon.

We're also Kissing Goodbye to our guilty pleasures to raise funds for MS research.

After an incredible first year in 2017, our Kiss Goodbye to MS campaign is back. We'd love you to help by sharing social media posts and encouraging even more people to Kiss Goodbye to their guilty pleasure. You can find out more at mssociety.org.uk/kissgoodbye

Audience: All Action: Share

Contact: Fundraising team fundraising@mssociety.org.uk 0300 500 8084

# Info and resources

### **MS Active Together**

The second phase of MS Active Together launched at the end of January.

We know that physical activity can improve everything from mobility and mood, to fatigue and balance. The campaign aims to inspire and encourage people living with MS to be more physically active.

We've produced a series of videos to help people get more physically active and manage symptoms:

- · Three thirty-minute Pilates videos
- Five three-minute videos with easy-to-follow exercises, with one video for each of the most common symptoms of MS filmed with a physiotherapist
- A Facebook Live Pilates class followed by a Q&A on 15 January.

So far, over 23,000 people have watched our Facebook live Pilates class and we've had over 7,300 views across our website and Youtube videos (...and still counting!)

#### Share your tips

Does your group organise classes? You might find exercise more enjoyable in a group.
And 'little but often' makes all the difference!

We'd love to hear what you do to stay active. To share your pictures, ideas and inspiration with people living with MS please get in touch on the details below.

Audience: All
Action: Share
Contact:

msactivetogether@mssociety.org.uk

### **Update on our publications**

We had a busy year in 2017. We distributed over 108,500 copies of our free printed publications – that's 17% more than in 2016!

So what did people want to know about? Our top 10 most popular publications were:

- 1. Managing a relapse
- 2. Claiming PIP (Personal Independence Payment)
- 3. Work and MS
- 4. Disease modifying therapies (DMTs) for MS
- 5. MS and your emotions
- 6. Living with the effects of MS
- 7. MS assistance card
- 8. Claiming ESA (Employment and Support Allowance)
- 9. Diet and nutrition
- 10. MS in the workplace: an employer's guide

#### **Online resources**

In the second half of 2017, our information resources were downloaded from our website a record 21,830 times. The most popular were:

- 1. Claiming PIP (Personal Independence Payment)
- 2. Have I got MS? And why is it taking so long to find out (download only factsheet)
- 3. Disease modifying therapies (DMTs) for MS
- 4. Understanding relapsing MS
- 5. Just diagnosed
- Hot and cold: the effects of temperature on MS (download only factsheet)
- 7. Managing the bowel
- 8. Understanding progressive MS
- 9. Living with MS
- 10. MS in the workplace

You'll find an up to date list of all our publications under the support section of our website.

Audience: All Action: Share

Contact: Information team

020 8438 0799



For group volunteers and national support group committee members

# TUUU Research

# Meet the people behind the breakthroughs

Scientific breakthroughs don't happen on their own. Behind every discovery is a researcher, or more likely, a whole team of researchers. Have you ever wondered who these people are? Or what motivates them? We've been asking our amazing researchers to talk about what they do – and why – in a new series of videos.



We're heading around the country, meeting researchers in their labs and at scientific conferences like MS Frontiers. You'll hear from a range of MS professionals, from our most eminent professors, to PhD students just starting out in their careers as MS researchers.

Between them, they'll be explaining many of the most important areas of our work, from physiotherapy to neuroscience. Many also share an insight into what drives them personally.

Videos of our fantastic researchers at the MS Society Cambridge Centre for Myelin Repair are now available at youtube.com/MSSociety.

They talk to us about the importance of myelin repair, and exciting new research that's bringing us closer to finding a treatment that can help everyone with MS.

Keep an eye out for the opportunity to meet more of our researchers throughout the year!

Audience: All
Action: Share

Contact: Supporter Care supportercare@mssociety.org.uk

0300 500 8084

# Digesting Science Ambassador training

Our Digesting Science team are excited to announce a new course taking place in May to train new Digesting Science Ambassadors – and we're looking for volunteers.

Explaining MS to children isn't easy. But Digesting Science Ambassadors can help to get the conversation started.

Digesting Science is a fun and interactive programme of activities that teaches 6-12 year olds about multiple sclerosis. The events are run in local communities and intended for children and families affected by MS.

This free two-day training course, delivered by the Barts-MS team, will equip you with the resources, skills and confidence you need to become a Digesting Science Ambassador and bring the programme to people affected by MS in your local community.

The course will be held at Queen Mary University of London on Wednesday 2 and Thursday 3 May 2018.

Refreshments are provided and reimbursement for travel and accommodation is also available.

Audience: All Action: Share

Contact: Digesting Science bookings@digestingscience.co.uk



### **Direct Marketing update**

#### Christmas appeal

Our Christmas Appeal was sent to 65,000 supporters in November. We talked about four different studies and re-purposing existing drugs to speed up the research process. Thanks to our amazing supporters, the appeal successfully raised almost £280,000 for vital MS research.

#### Spring raffle

Our Spring raffle was sent out on Saturday 3 March, with over £6,000 worth of prizes up for grabs for just £1 per ticket! The raffle closing date is Friday 4 May and online entries will remain open until Thursday 10 May. The draw will take place on Friday 11 May, and we're hoping to raise £140,000.

#### Gift Aid mailing

We sent a letter to supporters this month, asking them to Gift Aid their donations. This means, that the gifts they make in future, will be worth 25% more for the MS Society at no extra cost.

#### Legacy prospecting mailing

We also sent a Legacy mailing to 9,000 supporters in mid-February. In the letter we asked supporters to share their thoughts on leaving a legacy to the MS Society, and highlight the ways we can help supporters to make or update their Will.

Audience: All
Action: Share

Contact: Supporter Care supportercare@mssociety.org.uk 0300 500 8084

# Upcoming Legacy events in London and Edinburgh

Our MS Research: Past, Present, and Future events will be taking place in London and Edinburgh this Spring.

The events will provide a summary of our achievements in MS, as well as sharing information about our current research projects, and aspirations for MS treatments in the future.

Those who attend will also find out about how we fund research and will be given the opportunity to consider supporting MS research by leaving a gift in their Will.

Events will be taking place in:

- London, King's College:
   Tuesday 10 April, 10.30am 2pm
- Edinburgh, Royal College of Surgeons:
   Wednesday 9 May, 10.30am 2pm

If you'd like more information about our MS Research: Past, Present and Future events, or if you'd like to attend please contact Adam West on the details below.

Audience: All
Action: Share

Contact: Adam West, Legacy and In Memory Manager adam.west@mssociety.org.uk 020 8827 0374



#### 2017 Year end

A big thank you to all of you for all your support and patience throughout our busiest time of year!

As you're aware, 2017 was the first year that all our groups used Online Accounting – and it's made a huge difference to our processes. We'll work together with you to make 2018 an even better year.

Now that you've mastered Online Accounting, let's keep the momentum going and use it to analyse group transactions on a monthly basis.

Analysing monthly ensures that we can improve the accuracy of the information we report to HMRC within our quarterly VAT return, in financial reports for our trustees, and comply with our Financial Rules. For more information, you can find our Finance Handbook on our volunteer website at volunteers.mssociety.org.uk/finance-handbook

Audience: Finance Volunteers

Action: Note

**Contact:** Finance team

financesupport@mssociety.org.uk

0131 335 4078 0208 438 0875

#### **Cash collections**

After all that hard work collecting cash, our supporters need to know that their donations are secure and will be used for the purpose for which they were given. Here are a few ways you can make sure cash is safeguarded:

- It's time to consult the collection box location log! Please open, count and bank the contents of all boxes regularly. They also need to be checked to ensure they're tamper proof and secure.
- The collection box log should contain a note of the location of each box or bucket and these should all be numbered consecutively. Permission from business owners need to be obtained for static boxes.
- Only official MS Society collection tins and buckets can be used for collections.
- Street collections are likely to require a licence.
   Contact your local authority licensing department for advice.
- Cash collections must be counted by at least two people, and should never be left unattended in an unsecure area. The amount raised should be published in a group newsletter, or similar publication.
- Remember not to deduct any expenses from cash collected. All donations must be banked in full.
- Cash collected must be banked into your group bank account as soon as possible.
   If you're unable to bank cash on the same day as your collection, please make sure it's locked away securely.
- At the earliest possible date a reconciliation needs to be carried out between the cash banked and any income summaries you completed when counting the cash.

Audience: Finance Volunteers

Action: Share

Contact: Samantha More,
Senior Divisional Accountant
samantha.More@mssociety.org.uk



### **Meet the Team**

#### Tim Collins - Finance Business Partner

I am one of our Finance Business Partners and have been working here for over a year. I work with the CEO, Finance Strategy & Impact, MSS Cymru, MSS Northern Ireland, Philanthropy & Partnerships, Research and External Affairs directorates on their monthly Management Accounts, budgets, quarterly forecasts and help with any other Finance queries they may have. Previously I have worked at World Animal Protection, Macmillan Cancer Support and when I was living in New York, at the National MS Society of America.

#### Shaz Kobra – Finance Business Partner

I have worked in the charity sector for over 8 years now, I was at NSPCC prior to joining MS Society. I am the Finance Business Partner for Fundraising, Engagement, Services and Support, People and Scotland directorate. I work closely with budget holders to help them maintain their budgets, provide advice and analysis where necessary. I am the point of contact for these directorates, aiding with budget codes, updates on monies raised for research projects, forecasting, and monthly management accounts.

Audience: Finance Volunteers

Action: Note

# Online Accounting software upgrade

An upgrade to the Online Accounting software will be taking place on Tuesday 27 March.

If you've planned a co-ordinating team meeting for either Tuesday 27 or Wednesday 28 March, we recommend that you print out the required reports from Online Accounting beforehand, as you won't be able to access the system while the upgrade is taking place.

Further information about the upgrade will be posted on the Online Accounting notice board. If you have any questions please contact our Finance team.

Audience: Finance Volunteers

Action: Share

Contact: Finance team

financesupport@mssociety.org.uk

0131 335 4078 0208 438 0875



# Global Banking Authority form update

As you may be aware, Barclays have recently updated their Global Banking Authority form (bank mandate). We've produced a new set of guidelines to help you complete it.

If you wish to change your bank account signatories please use this form as Barclays will no longer be accepting the old version.

Please request banking documents from our Finance team rather than your local branch or the Client Service Executive Team. Barclays often update their forms, and our Group Finance Support Team will always have the correct version.

Audience: Finance Volunteers

Action: Share

Contact: Finance team

financesupport@mssociety.org.uk

0131 335 4078 0208 438 0875

### **Charities Aid Foundation**

There are lots of different ways to make a donation. One way is through a Charities Aid Foundation (CAF) charity voucher.

When your group receives a CAF voucher, you will need to:

- Email or post a copy of the voucher to treasurysupport@mssociety.org.uk
- 2. Fill in the boxes on the front of the voucher with your group's details. If the voucher only asks for a beneficiary account number, please enter '41000352053'.

The amount on the voucher is reimbursed to MS Society National Centre and using the information you've provided, the funds are earmarked to your group.

There are cases where funds are sent directly to MS Society National Centre from companies that your group works with. When you receive a notification from a company that a CAF payment has been made, please let us know by emailing treasurysupport@mssociety.org.uk so we can earmark the funds to your group.

Audience: Finance Volunteers

Action: Share

Contact: Treasury Support

treasurysupport@mssociety.org.uk



# Take a leap on the wild side and help stop MS



Would you or someone you know like to join our team of daredevils and take the leap of a lifetime at our exclusive MS Society skydiving day – The Big Leap?

On Sunday 2 September, you can feel the thrill of jumping from 13,000 feet and free-falling at over 120mph while raising vital funds for our MS community.

The Big Leap takes place at Hinton Skydiving Centre in Brackley, Northants. Our skydives are accessible and open to everyone.

If this sounds like the perfect challenge you can find out more at mssociety.org.uk/ms-events/big-leap or contact our Fundraising team on the details below.

Audience: All
Action: Share

Contact: Fundraising team challenge@mssociety.org.uk
0300 500 8084

# Our #MSSuperstars need you!

Could you cheer on our fantastic runners at one of our upcoming events? Hundreds of runners will be pounding the pavements this year, to stop MS in its tracks. Let's show them our support!



We're looking for volunteers to join our cheering squads at the following events:

- London Landmarks (central London) Sunday 25 March
- Brighton Marathon (Brighton seafront) Sunday 15 April
- London Marathon (central London) Sunday 22 April
- Great Manchester Run (city centre) Sunday 20 May

If you'd like to cheer – or know someone who would – please contact our Fundraising team.

Audience: All
Action: Share

Contact: Fundraising team challenge@mssociety.org.uk

0300 500 8084





### For Northern Ireland

#### **IT Matters**

Would you or any volunteers in your group like to learn new IT skills? Or brush up on your existing skills?

We're delighted to have received funding from the Big Lottery Awards for All programme, to offer 'IT Matters' – a fantastic new course to hone your computer skills.

From using social media, Outlook for email and Web to Print to accessing the MS Portal – you'll be having fun while you learn in a relaxed and friendly atmosphere.

Sessions take place weekly, for six weeks and are being held across Northern Ireland:

- Omagh starting on Monday 9 April
- Belfast starting on Wednesday 11 April
- Ballymena starting in September (date TBC)
- Craigavon starting in September (date TBC)

Your LNO will be in touch with additional information, but if you have any questions, or would like to sign up straight away, please contact the Northern Ireland Network Team.

Audience: Northern Ireland

Action: Share

Contact: Northern Ireland Network team NINetworkTeam@mssociety.org.uk

#### Research talks

Our research events bring together people living with MS, expert researchers and MS professionals to discuss the latest developments in MS research.



We're at the start of a generation of MS research that holds incredible promise – and we want this promise to become reality.

We'll be holding two research talks this spring, to give you up to date information about our research projects, as well as access to the brightest minds in MS research.

- Derry, Everglades Hotel:
   Friday 11 May 2.30pm 6pm
- Belfast, Crowne Plaza:
   Saturday 12 May 10.30am 2.30pm

You'll find out more about a study from Genomics Medicine Ireland that is looking at the genomic basis of MS and Lynn Duffy, our Research Communications Officer, will be providing a round up of MS research.

Online registration will open soon. If you have any questions, or would like to pre-register to attend, please contact our reception.

Audience: Northern Ireland

Action: Share

**Contact:** NI reception

nireception@mssociety.org.uk

028 9080 2802





### For Northern Ireland

# Welfare and benefits: our MS Enough campaign

Nearly one in three people with MS who apply for Personal Independence Payment (PIP) for the first time are refused.

As part of our MS Enough campaign, in Northern Ireland we've spoken to Capita (who carry out PIP assessments), and the Department of Communities (who are responsible for the benefit). We've shared with them the difficulties many people living with MS have experienced with the system.

We've also put forward proposals about how things can be improved. They highlight issues in transparency, the use and consistency of medical evidence and the creation of an MS Champion for Northern Ireland.

There is also an ongoing independent review of PIP which we'll continue to influence right to up to publication in June.

As the welfare system is so important to our community, we'll be hosting an event in September about benefits. You'll be able to find out more about changes to the benefits system, including those that have happened – and those yet to come, as well as how you can be involved in making things better in future.

For more information please contact Stewart Finn.

Audience: Northern Ireland

Action: Share

**Contact:** Stewart Finn,

Press, Policy and Campaigns Manager

stewart.finn@mssociety.org.uk

### **Getting involved**

We run a calendar of events which are an excellent opportunity to raise funds for your group, have fun and bring supporters together at one of our fantastic events.

#### **Fundraising events**

From the Belfast Marathon, Tough Mudder run, abseils, zip-slides to moonlight walks, our jam-packed calendar has something for everyone. Whether you've been inspired to take part, or you want to volunteer to cheer or help out on the day, however you choose to support our events, we'd be delighted to have you on board. We provide all of the organisation, logistics and support you need to get involved.

#### **Digesting Science**

Digesting Science is a fantastic and fun activity day for families and children of people

living with MS aged 6-12 years old.

Through a series of interactive experiments, children and young people can learn about MS. We're looking for groups to get involved and organise Digesting Science sessions for families they know.

#### More dates for your diary

You can also join in with:

- Family Fun Day Saturday 23 June
- Support Volunteer Forums – Omagh, Monday 21 May
- Support Volunteer Forum – Belfast, Tuesday 22 May



To find out more, or sign up for any of the events outlined above, please contact Tom Mallon.

Audience: Northern Ireland

Action: Share

Contact: Tom Mallon, Fundraising Manager tom.mallon@mssociety.org.uk





### For Scotland

# Scotland income tax changes and Gift Aid

In December, Scotland's finance minister announced changes to income tax that will add two extra tax bands. This could affect the Gift Aid scheme in Scotland in two ways:

- how much we can reclaim from HMRC on donations
- 2. what Gift Aid declarations say

Charities are working hard with HMRC to make sure that the Gift Aid scheme in Scotland can remain running efficiently.

If your group claims Gift Aid, please continue to do so as normal.

We'll update you as soon as we've received further guidance from HMRC.

Audience: Scotland
Action: Share

Contact: Supporter Care

supportercare@mssociety.org.uk

# Getting loud for research this MS Week

We'll be getting loud for MS research in Scotland during MS Week (23-29 April) this year.

Our Spring campaign will be kicking off this MS Week, as well as Kiss Goodbye to MS (see p. 7). In Scotland, we'll also be shining a spotlight on advances in treatments, MS research and the great work of researchers in Scotland.

We'll be holding a reception in the Scottish Parliament. MSPs will hear first-hand about the impact MS research has had on people's lives, and why campaigns like Kiss Goodbye to MS can make a real difference. We're also planning a debate in parliament and hope to secure media coverage throughout the week.

We've made huge strides in MS research over the past 20 years. In Scotland, 13 disease modifying therapies (DMTs) are available for people with relapsing MS – with more in the pipeline. Later this year ocrelizumab will be assessed by the Scottish Medicines Consortium for both relapsing MS and early primary progressive MS. If successful, this will be the first DMT available for some people with primary progressive MS. But we can only continue to make breakthroughs like these, with your support.

Has access to treatments had a positive impact on your life? Share your story and help us show how important research and new treatments are for people living with MS.

Audience: Scotland

**Action:** Share

Contact: Niall Sommerville, Policy, Public Affairs and Campaigns Manager scotlandcampaigns@mssociety.org.uk





### For Scotland

### Fundraising this spring

Here's two brilliant ways for you, and those you're in touch with, to get involved with fundraising this spring!

### Join our Volun*cheer* Squad at the Edinburgh Marathon Festival

We have over 100 #MSSuperstar runners taking part in the Edinburgh Marathon Festival to help stop MS – and we want to make sure they feel fantastic!

Join our Voluncheer Squad on Sunday 27 May and help cheer them over the finish line.

Every member of our Voluncheer Squad gets an orange-tastic MS Society t-shirt, cheer sticks and flags – plus lunch and snacks to keep your energy levels up. It's a great way to enjoy the atmosphere of this brilliant event.

#### Take on the Zipslide Zinger

Do you fancy doing something that gets your heart racing and your feet off the ground?

We'd love you to join the #MSSuperstars team in our fully accessible Zipslide Zinger - which is fun for the whole family (from ages 6+). It'll be a day full of adrenalin and fun, with lots to celebrate as you zoom to the finish!

The Zipslide Zinger takes place on Saturday 5 May at Crieff Hydro, Perthshire.

For more information or to sign up, contact our Fundraising team.

Audience: Scotland

Action: Share

Contact: Rhianna Adams,
Fundraising Assistant
msfundraising@mssociety.org.uk

0131 335 4063

### New Year's Honours: John Caskie and Stuart Rose

We're delighted to announce that Dumfries super-volunteer **John Caskie** has been honoured with an MBE for services to the community in Dumfries.

John first supported us when he was at school. After his aunt was diagnosed with MS, John's family got involved with our group, where John was Chair for a number of years.

Inspired by his aunt's love of Scottish country dancing, John organised a dance to raise funds. It ran every year for the next 25 years, raising funds – and awareness. John, who supports many local causes, said:

"If I can do my bit and help out I will. I don't do it for the reward. I was humbled, proud and excited to receive an MBE."

And the good news continues! Inverness superstar **Stuart Rose** who has raised over £52,000 for the MS Society since he started fundraising in 2011, was also honoured this year, with a British Empire Medal.

Stuart, who was diagnosed with MS aged 15 and uses social media and blogging to raise awareness, said:

"I was proud and honoured, but also a bit embarrassed as I never do it for the recognition. It means a lot to have people believe in me. When someone sends a simple message saying what impact I've had on them or how they appreciate the awareness I raise – every little bit of support is hugely important".

You can read more about Stuart in our MS Matters feature story – out at the end of March .

Congratulations and a huge thank you to John and Stuart.

Audience: Scotland

Action: Share





### My MS My Rights, My Choices Project

Since last year, 640 people have attended one of our My MS, My Rights, My Choices events. There are around 5,000 people living with MS in Wales, so this is a tremendous achievement. Thanks to the support of the Big Lottery Fund and Masonic Charitable Foundation, you can also join one of our fantastic events:

#### **Newly Diagnosed Days**

- Swansea – Friday 20 April, Mercure Hotel

#### **Getting Active Events**

 Newtown – Sunday 15 April, Newtown Leisure Centre

#### **Benefits and Grants Events**

- Llandudno Tuesday 17 April, Venue Cymru
- Aberystwyth Monday 23 April / Friday 27 April, National Library of Wales
- Wrexham Wednesday 9 May, Ramada Hotel

#### Information Events

- Connah's Quay, Flintshire Tuesday 15 May, Kathleen & May Centre
- Wrexham (Digesting Science event) Wednesday May 30, Ramada Hotel
- Llandudno (Digesting Science event) Thursday May 31, Venue Cymru

To register or for more information please do get in touch with the team.

Audience: Wales
Action: Share

Contact: My MS, My Rights, My Choices team mymscymru@mssociety.org.uk **Key dates** 

The MS Society Cymru Council is a group of volunteers who represent people living with MS in Wales, and work on their behalf. The Council will be meeting three times this year.

Open evenings provide a great opportunity to meet council members and staff, and learn about the latest news and activities.

	Open	Council	
	Evening	Meeting	
Carmarthen	12 April	13 April	
Llandrindod Wells	9 August	10 August	
Wrexham	19 October	20 October	

### Run or cheer at the Cardiff Half Marathon – 7 October

Registration is now open for the Cardiff Half Marathon.

Please help us spread the word and do get in touch if you or someone you know would like to volunteer to cheer. Our cheerers make a huge difference to our runners on the day!

Audience: Wales
Action: Share

Contact: Council meetings

Matthew Witty,

Executive Assistant to Director of Wales matthew.witty@mssociety.org.uk

Cardiff marathon

Sian Dorward, Fundraising Manager sian.dorward@mssociety.org.uk



### Social Care in Wales - share your opinion

The Wales Neurological Alliance is collecting information from people living with neurological conditions about their experience of social care.

We need your help to publicise the survey to your group members.

Could you include the following information in your newsletters and social media pages?

#### Share your voice on social care

The Social Services and Well-being (Wales) Act has now been law in Wales since the 6th April 2016. This Act aims to transform the way that social services are delivered in Wales and contains important new legal rights for people who use the services.

The Wales Neurological Alliance want people with neurological conditions across Wales to help us follow the progress of the Act so we can see what's making a difference to your life, and what more needs to be done. Please complete our short survey and tell us about your experiences.

https://www.surveymonkey.co.uk/r/9KGKTGW

#### Rhannwch eich barn ar ofal cymdeithasol

Erbyn hyn mae Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) wedi bod mewn grym yng Nghymru ers 6 Ebrill 2016.

Nod y Ddeddf hon yw gweddnewid y ffordd mae gwasanaethau cymdeithasol yn cael eu cyflenwi yng Nghymru ac mae'n cynnwys hawliau cyfreithiol newydd pwysig i pobl gyda phroblemau niwrolegol.

Rydym am i pobl gyda phroblemau niwrolegol ledled Cymru ein helpu ni i ddilyn y ddeddf, fel y gallwn weld beth sy'n gwneud gwahaniaeth i'ch bywyd, a beth yn rhagor sydd angen ei wneud. Ewch ati i gwblhau ein harolwg byr a dwedwch wrthym am eich profiadau.

https://www.surveymonkey.co.uk/r/9KGKTGW

Audience: Wales
Action: Share

Contact: Fiona McDonald, Policy, Press and Campaigns Manager

fiona.mcdonald@mssociety.org.uk



### **Group contributions**

Thank you to all groups for your contributions. They are all gratefully received.

Group contributions 22/11/17 to 01/02/18							
Group Name	Earmarked Description	Earmarked	Research	General			
Ballymena Group	MS Northern Ireland Day Centre	£2,000.00	£8,000.00				
Blackpool Group			£20,000.00				
Cambridge & District Group	Cambridge Myelin Repair Centre	£1,740.00					
Cheltenham & North Cotswold Group			£5,000.00				
Chesterfield & District Group			£5,000.00				
East Grinstead & District Group			£1,000.00				
Falkirk Group			£5,000.00				
Furness Group	Cambridge Myelin Repair Centre	£5,000.00					
Furness Group	Simvastatin phase III Project	£5,000.00					
Gosport & Fareham Group			£10,000.00				
Grimsby & District Group			£500.00				
Hull, Beverley & Holderness Group			£10,000.00				
Larne & East Antrim Group			£2,500.00				
Maldon & East Essex Group	Cambridge Myelin Repair Centre	£4,362.96					
Mendip Group			£235.50				
Merton Group			£262.27				
Montgomeryshire Group			£750.00				
Oldham & District Group	Cambridge Myelin Repair Centre	£1,000.00					
Peebles Group	MS Society Edinburgh Centre for MS	£5,000.00					



## Group contributions

Group Name	Earmarked Description	Earmarked	Research	General
Reading, Wokingham & Districts Group			£30,000.00	
Rhondda Cynon Taff Group	Cambridge Myelin Repair Centre	£1,000.00		
Rhondda Cynon Taff Group	Stem Cell	£1,000.00		
Ross-Shire Group			£2,000.00	
Shrewsbury & District Group			£5,000.00	
St Helens & District Group*	Progressive MS Alliance	£2,000.00		
St Helens & District Group*	Stem Cell Research	£1,000.00		
St Helens & District Group*	Cambridge Myelin Repair Centre	£1,000.00		
St Helens & District Group*	What factors affect the quality of life of people with MS?	£2,000.00		
Sutton (London Borough of) Group			£25,000.00	
Warrington & District Group			£500.00	
Winchester & District Group	Progressive MS	£2,500.00		
Worcester & District Group	Cambridge Myelin Repair Centre	£3,000.00		
Total		£37,602.96	£130,747.77	

<sup>\*</sup> The contributions from St Helens and District Group were made in 2016, but due to a technical error at MS National Centre weren't acknowledged at the time. Our apologies for the group for not reporting these earlier, and our thanks for these generous contributions.



# Holiday lodge and bungalow

The Bexley & Dartford group have a holiday lodge for people with MS and their families at Shorefield Holiday Village, Milford on Sea, near Lymington, Hampshire. The lodge is fully adapted for disabled people and wheelchair users, and has a master bedroom with en-suite shower room and hoist, a twin room, bathroom, and lounge/kitchen area with sofa bed.

The group also have a detached two bedroom bungalow at Eastbourne, Sussex, on a peaceful private estate close to Sovereign Harbour. Fully equipped (no fixed hoist) for people with MS and their families and furnished for 4/6 people.

For enquiries or bookings for 2018 for both properties, please contact the Bexley & Dartford group on 0208 306 7050 or email bexley@mssociety.org.uk.

#### **Share chalets**

The team in Northern Ireland have two fully accessible chalets for hire at the Share village in Lisknaskea on the tranquil shores of Upper Lough Erne in beautiful County Fermanagh.

Share is an outdoor activity centre open to everyone and with plenty of entertainment options for the whole family. Share works for the inclusion of disabled and non-disabled people by providing opportunities for all to participate in a wide range of recreational and creative activities.

We're able to offer our chalets at a much reduced rate to people with MS and their families. Our chalets sleep eight and come with access to the onsite fitness centre.

To find out more please contact NI reception at nireception@mssociety.org.uk or on 028 90 802 802.

Mention or advertisement by the MS Society of products or services is not an endorsement by the MS Society, its officers or staff.



### **Teamspirit directory**

### **Our offices**

#### **MS Society**

MS National Centre 372 Edgware Road London NW2 6ND 020 8438 0700

#### **MS Society Cymru**

Temple Court Cathedral Road Cardiff CF11 9HA 020 8438 0700

#### MS Society Northern Ireland

The Resource Centre 34 Annadale Avenue Belfast BT7 3JJ 02890 802 802

#### **MS Society Scotland**

National Office Ratho Park 88 Glasgow Road Ratho Station Newbridge EH28 8PP 0131 335 4050

# Feedback on Teamspirit

teamspirit@mssociety.org.uk

### **Support groups**

#### **Asian MS**

A national support group for Asian people with MS, their carers, friends and family asianms@mssociety.org.uk

#### **Mutual Support**

For serving and ex-serving members of the Armed Forces and Reserves affected by MS, their dependants and carers. support-team@mutual-support. org.uk

#### **Women Against MS**

Confidential support for women who have MS, their carers, families, friends and employers. Currently holding two information events a year. info@womenagainstms.org.uk 020 8542 1712

#### Find us online

mssociety.org.uk

volunteers.mssociety.org.uk facebook.com/mssociety twitter.com/mssocietyuk

#### Get in touch

#### **Supporter Care**

supportercare@mssociety.org.uk
0300 500 8084

#### **National MS Helpline**

helpline@mssociety.org.uk 0808 800 8000